
Plan Overview

A Data Management Plan created using DMPTuuli

Title: Physical activity and exercise for young people with cerebral palsy: understanding mechanisms and providing evidence of efficacy (EXECP)

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Template: General Finnish DMP template

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Project abstract:

Cerebral palsy (CP) is the most predominant childhood disability characterized by neural impairments. Evidence-based interventions are in pivotal role when developing targeted rehabilitation for people with CP, aiming to maintain their motor function and wellbeing through life. The overarching aim of this project is to study the effects of a multi-component EXECP-intervention on gait, mobility, PA, body functions and neuromuscular mechanisms in children and young adults with CP. With a multidisciplinary approach, we study central and peripheral nervous system functions, in order to advance the understanding of adaptive mechanisms in CP. To facilitate translation of results from bench to bedside, policy and practice, we will give lectures for stakeholders, students and clinical community and open a digital forum for individuals where researchers answer questions about exercise training in people with CP.

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Physical activity and exercise for young people with cerebral palsy: understanding mechanisms and providing evidence of efficacy (EXECP)

1. General description of the data

1.1 What kinds of data is your research based on? What data will be collected, produced or reused? What file formats will the data be in? Additionally, give a rough estimate of the size of the data produced/collected.

Data has been collected by questionnaires and tests during visits to laboratory, and during daily living in participant's normal living environment. Questionnaire data will be digitalized into Microsoft Excel worksheets. Blood sample data will also be stored into an excel spreadsheet.

In laboratory, analogue force, joint angle and muscle electromyographic activity data is collected and digitalized using 16 bit AD-board (CED, Cambridge, UK) before storing using Spike software as .smr format from which it can be exported as common data types (e.g. to Matlab). Three dimensional gait analysis data (e.g. c3d) collected using AMT force plates and Vicon Nexus system. Outcome measures will be extracted using custom-made programs.

Daily physical activity is assessed using accelerometry which provides .dat files that are processed using custom-made software. The .dat files contain either headerless binary data or binary data including a proprietary header in proprietary format. These files are not accessible without the assistance from the manufacturer. We have worked with the manufacturer to implement custom-written file readers which will not be made public because we do not have the manufacturer's consent. The .dat files are associated with a particular participant based on the folder name of the .dat file and a key file linking the folder names to participants. In data processing we can also utilize CSC services for large data management and processing. Daily muscle activity assessed using EMG pants provides us a database to Megawin software where we can extract the data and export it as *.csv for later processing in Matlab.

1.2 How will the consistency and quality of data be controlled?

The research material will be carefully maintained, documented and stored in the servers of the Information Management Center of the University of Jyväskylä. Quality of obtained data is ensured by training the persons performing the assessments. Researchers involved in data collection are given specific tasks to manage data documentation. All original data is kept untouched in designated folders and for processed data subfolders are created. Such folder structure is systematically used and explained in the metadata file. Collection and processing of the data is described in the Instructions-folder of the EXECP-project. Original data is stored to its designated folder under each participant ID.

2. Ethical and legal compliance

2.1 What legal issues are related to your data management? (For example, GDPR and other legislation affecting data processing.)

The data are collected on children with cerebral palsy, thus the data are sensitive. Written consent will also be asked from legal guardians of participants under 18 years of age. For images and video material taken during the measurements, separate consent is obtained from the participant. Data will be pseudonymized and the identification-key to link identification number to personal identification information will be in the possession of the PI of EXECP (Tajja Juutinen) and PI of ISENS (FC) and a doctoral student Pedro Valadao. University of Jyväskylä has designated Data Protection Officer (DPO) and project data controller is Tajja Juutinen together with Pedro Valadao and Francesco Cenni. All data files will be stored on the University server and protected by individual usernames and passwords. The research data will be managed by the PI's and the doctoral student, or other researcher specifically appointed for this task.

We will carefully select variables if they are to be stored in an open access repository such that anonymity can be confirmed (e.g variables from rare individuals possibly identifiable will not be making accessible). The research project ends in December 2025 when the identification-key will be destroyed thus converting data towards anonymization. In the anonymization process, individual-specific rare variables that can reveal identity in this small sample will be deleted.

2.2 How will you manage the rights of the data you use, produce and share?

Ownership of the data belongs to the University of Jyväskylä and there are no limitations or third party rights regarding background or foreground of the project. Agreements about sharing (if needed) and publishing data will be formalized. Vancouver protocol will be followed for authorships in publications.

3. Documentation and metadata

3.1 How will you document your data in order to make it findable, accessible, interoperable and re-usable for you and others? What kind of metadata standards, README files or other documentation will you use to help others to understand and use your data?

We have prepared documentation about data collection, instrumentation, and analysis procedures where file-specific analysis-flows and descriptions are contained. The designated EXECP-project folder has a structure according to file "Data structure.xlsx".

Similarly, processed data has designated folders for each phase. Information of data availability is updated upon manuscript submission.

The data was anonymised 18.8.2023 and the data included in publications is published in the Open Science Framework repository <https://osf.io/4kbjh/>

4. Storage and backup during the research project

4.1 Where will your data be stored, and how will the data be backed up?

Data is stored on the University server to its designated folder and protected by individual username and password. JYU has centrally managed backup system.

4.2 Who will be responsible for controlling access to your data, and how will secured access be controlled?

Access to the data is controlled by EXECP project PI Tajja Juutinen who can grant and deny access to the data.

5. Opening, publishing and archiving the data after the research project

5.1 What part of the data can be made openly available or published? Where and when will the data, or its metadata, be made available?

Metadata (owners, project description, data collection and processing procedures, and list of variables) will be made available either in the form of publication or as information stored into database provided by the University (Coveris).

5.2 Where will data with long-term value be preserved, and for how long?

The data will be pseudonymized upon data collection by using identification numbers instead of individuals' name in files and documents. When the research project ends in December 2025, the identification-key will be destroyed, thus converting data towards anonymization. In the anonymization process, individual-specific rare variables that can reveal identity in this small sample will be deleted. Anonymous data will be stored in an open access repository (e.g. JYX).

6. Data management responsibilities and resources

6.1 Who (for example role, position, and institution) will be responsible for data management?

Taija Juutinen, professor, University of Jyväskylä, Finland
Pedro Valadao, PhD student, University of Jyväskylä, Finland
Francesco Cenni, Postdoctoral fellow, University of Jyväskylä, Finland

6.2 What resources will be required for your data management procedures to ensure that the data can be opened and preserved according to FAIR principles (Findable, Accessible, Interoperable, Re-usable)?

Most of the preparation of data has already been done while collecting, processing and analyzing the data. We aim to use Coveris at University of Jyväskylä to store the metadata. The documentation will be continuously updated during the study together with the data analysis with estimated time spent about 1 hour per month. Final preparation of the data and publishing it will require about 30 hours. This will be supported by Open Science Center of University of Jyväskylä. Anonymization of personal data will require about 10 hours.